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# **'HANGING IN A BALANCE': A QUALITATIVE STUDY EXPLORING CLINICIANS' EXPERIENCES OF PROVIDING CARE AT THE END OF LIFE IN THE BURN UNIT**

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## **ABSTRACT**

**Background:** Although the culture in burns/ critical care units are gradually evolving to support the delivery of palliative/ end of life care, how clinicians experience the end of life phase in the burn unit remains minimally explored with a general lack of guidelines to support them.

**Aim:** To explore the end of life care experiences of burn care staff and ascertain how their experiences can facilitate the development of clinical guidelines.

**Design:** Interpretive-descriptive qualitative approach with a sequential two phased multiple data collection strategies was employed (face to face semi-structured in-depth interviews and follow-up consultative meeting). Thematic analysis was used to analyze the data.

**Setting/ participants:** The study was undertaken in a large teaching hospital in Ghana. 20 burn care staff who had a minimum of 6 months working experience completed the interviews and 22 practitioners participated in the consultative meeting.

**Results:** Experiences of burn care staff are complex with four themes emerging:1) evaluating injury severity and prognostication 2) nature of existing system of care 3) perceived patient needs 4) considerations for palliative care in burns. Guidelines in this regard should focus on facilitating communication between the patient and family and staff, holistic symptom management at the end of life, and post-bereavement support for family members and burn care practitioners.

**Conclusions:** The end of life period in the burn unit is poorly defined coupled with prognostic uncertainty. Collaborative model of practice and further training are required to support the integration of palliative care in the burn unit.

**Keywords:** burns; end of life; palliative care

### **What is already known about the topic?**

- The immediacy of death in the burn unit is usually in the order of hours or days requiring the timely application of palliative care
- Although the culture of burns/ critical care units is evolving the support the integration of palliative care, several barriers such as prognostication and lack of guidelines exist
- Clinicians working in burn/ critical care units may experience emotional exhaustion

### **What this paper adds?**

- The findings suggest a complex decision-making process which may delay the initiation of comfort care
- Collaboration with palliative care practitioners and training are required to support the integration of palliative care in the burn unit.
- Guidelines to support the delivery of palliative care may focus on communication, symptom management, and post-bereavement support for families and staff.

### **Implications for practice, theory, and policy**

- A collaborative model of care is required to support palliative care integration in the burn unit
- Palliative care for severely burned patients may need to commence alongside active burns management

## Introduction

Burns are sudden events representing a severe form of physical trauma.<sup>1</sup> Despite advances in burn care, some patients may not survive the injury.<sup>2</sup> The World Health Organization (WHO) has reported 180,000 deaths from burns annually with most of these occurring in low- and middle-income countries.<sup>3</sup> Current statistics suggest that approximately 40,000 persons are hospitalized with burns annually in the United States of America with over 3000 patients succumbing to death.<sup>1, 4</sup> Australian population-based studies from 1980 to 2012 reported long-term mortality rates as high as 42% among older adults and 1.6% greater mortality risk among paediatric burn survivors.<sup>5-7</sup>

Death in the burn unit can be classified as early (within 24-72 hours post-admission) or late (death following a period of active treatment).<sup>8</sup> Withholding active treatment for persons in the former category, if ascertained early, can lead to the timely commencement of comfort care within the limited period of hospitalisation. Persons in the late death category may survive the injury for a period before active therapy is withdrawn.<sup>9</sup> Irrespective of the category, the timing of comfort care usually follows a futility decision which may be limited to the final days/ hours.<sup>10</sup> Thus, although palliative care differs from end of life care, the limited timeframe which may run the short duration of the burn injury trajectory or limited to the final days following withdrawal of active treatment suggests that both may overlap in burns management.<sup>8, 9, 10</sup>

The culture of burn care and other critical care settings is evolving to support the delivery of palliative care to alleviate health-related suffering.<sup>11</sup> However, significant gaps exist regarding how best to fully integrate palliative care in these areas.<sup>12-14</sup> Concerns regarding prognostication, communication, clinicians' perceptions and lack of guidelines have been identified as significant barriers.<sup>11</sup> Within the burn unit, several studies have also highlighted a lack of clinical guidelines and limited understanding of the clinicians' experiences at the end of life.<sup>8, 10, 15, 16</sup>

Critical care units are often characterised by significant stress<sup>17</sup> and moral distress.<sup>18, 19</sup> Staff working in burn/ critical care units may experience depersonalization and high rates of emotional exhaustion when care is perceived to be futile.<sup>20, 21</sup> Besides, transitioning from active treatment to comfort care in the burn unit may occur suddenly and contribute to the experience of distress.<sup>22</sup> Despite these, it remains unclear how burn care staff experience the end of life phase. Thus, this study sought to explore the experiences of staff in delivering care following admission in the burn unit to the end of life phase and to ascertain how their experiences could inform the development of guidelines applicable to burn care.

## **Methods**

### ***Research question***

What are the experiences of healthcare professionals in providing end of life care in the burn unit and how can their experiences inform the development of clinical guidelines?

### ***Design***

Interpretive description qualitative design with a sequential multi-method two-phased data collection approach was employed.<sup>23</sup> Interpretive description is an inductive approach which assumes the existence of multiple realities.<sup>23</sup> Interpretive description was utilized due to its focus on understanding clinical phenomenon. The multi-method data collection approach was utilized to gain a fuller picture of clinicians' experiences and validate summative findings. The first phase involved the use of face to face semi-structured interviews. In the second phase, a consultative meeting was conducted to discuss how the experiences should inform the development of guidelines.

### ***Study Setting***

The study was undertaken in a teaching hospital in Ghana. The facility was chosen because it has a large referral catchment area covering the entire middle and northern parts of the country. Additionally, the facility houses one of the two burn units in the country.

### ***Participants***

Burn care staff were invited to participate from March to August 2019. Participants were considered eligible if they have worked for a minimum of 6 months in the burn unit and were willing to participate. Staff who were on leave were excluded from the study.

### ***Sampling***

Purposive sampling was used to recruit a heterogenous sample of staff based on the gender, professional group and number of months worked.

### ***Recruitment***

Following approval, the study was advertised in the unit. Eligible staff were also approached to discuss the study. We provided a two-week period for staff to provide their feedback. Following confirmation to participate, GA or PKB completed the consent process.

### ***Data Collection***

Semi-structured interviews were conducted using an interview guide. All interviews were conducted in English by two burn care nurses (GA and PKB) in the departmental seminar room. Each interview started with a broad question "what has been your experience providing care in the burn unit"? The interview progressed based on responses but ultimately covered questions on end of life care, experiences with family members, discussing mortality risk and perceived needs. Follow-up interviews were utilized to discuss the emergent themes. Data saturation (when no new information emerged from the interviews) was apparent after the nineteenth interview and confirmed with the twentieth interview. After the interviews, a follow-up consultative meeting in the form of a group discussion was held and moderated by JB. Two practitioners in administrative roles participated in the meeting.

### ***Ethical Considerations***

Ethical approval was obtained from Kings College, London (HR-17/18-5408) and Komfo Anokye Teaching Hospital (KATH-IRB/AP/024). Consented participants signed a written informed consent which included participation in both phases.

### ***Rigour***

Lincoln and Guba's framework was used to attain rigour.<sup>24</sup> Prolonged engagement with participants and utilization of probes enabled in-depth exploration. Interviews and consultative meeting were moderated by burn care nurses. Data analysis was undertaken by two nurses with expertise in qualitative research. Ongoing consultation with the team ensured that the study was conducted rigorously.

## **Analysis**

Interviews and consultative meeting were audio recorded and transcribed in the Trint Automated Transcription Software. All transcripts were exported to QSR NVivo 10 and analyzed using thematic analysis.<sup>25</sup> The analysis was undertaken by two nurses (JB & FBA) alongside ongoing discussion with RH, KB, FKYW and AEA. JB & FBA read the transcripts for familiarization with the data and undertook a line by line coding to inductively generate initial codes. Subthemes were formulated from similar codes. Similar subthemes were grouped to develop themes and reviewed by the team.

## **Results**

### ***Characteristics of participants***

Twenty (20) clinicians participated in the interviews, with two additional practitioners participating in the consultative meeting (Table 1).

**Table 1: Characteristics of Participants**

### ***Findings***

Four themes and twelve subthemes emerged (Table 2). Informants are presented as: Registered Nurse (RN), Nursing Assistant (NA), Physician (PHY) and Physiotherapist (PT). The first round of interviews lasted 21-46 minutes with the follow-up interviews lasting 4-10 minutes. The follow-up consultative meeting lasted for 52 minutes.

**Table 2: Themes and Subthemes**

## **Evaluating injury severity and prognostication**



Participants described the approach to ascertaining injury severity and mortality risk as described below:

### ***Physiological parameters***

Participants described patient's age to be crucial in prognostication. Participants considered persons of extreme age groups to be at high-risk for mortality following burns: *"And then the patients at the extremes of age limit, that is babies or elderly (RN004)".* Participants described persons with existing chronic conditions to be a high-risk group as the burns could worsen these conditions: *"Patients with conditions like hypertension can develop various complications." (PHY002)*

Participants described the extent of the injury as a factor in prognostication. Even though early excision/ grafting may reduce the risk of mortality, greater burn extent meant smaller proportion of skin remaining: *"...let's even say burns with total body surface area involved above 50%, the prognosis is not good because you cannot even get any skin" (PHY001).* Participants mentioned that some burns occurred alongside inhalational injury which compromised breathing: *"...some patients may have inhalational injuries which affect their breathing" (PHY003).* Participants emphasized their reliance on patient's laboratory tests to ascertain the possible outcome: *"the haemoglobin is low, albumin is low with poor LFT and RFT levels, then it tells you that this patient might not survive the injury." (RN0010).*

### ***Financial Status***

Participants mentioned that some burn patients/ families are unable to afford essential items needed for their care. Absence of these items were noted to adversely affect patient outcomes: *"Somebody is not able to make it because they cannot afford medication or dressing materials." (PT002)*

### ***Timing of reporting and Pre-hospital Care***

Participants mentioned that the time taken to seek healthcare in a well-equipped facility was critical in prognostication: *"...if they are brought to the hospital early, the patient can be intubated but if it is delayed, the airway gets blocked."* (RN003). Pre-hospital care was also considered to be crucial as participants highlighted that household substances were usually applied to the wound which increased the risk of mortality: *"People apply all manner of things to the wounds like eggs and soil which can even cause infection"* (RN007). Despite these parameters, participants admitted that accurate prognostication was still challenging, and felt that the individual outcomes were out of their control: *"...but then again firmly deciding whether someone will die or not is in the hands of God."* (PHY0003).

### **Nature of existing system of care**

Participants described the environment in which burn care occurs and the dynamics involved. These are described below:

#### ***Burn Care Environment***

Participants mentioned that the care provided was a mix of acute and critical care. The patients catered for in this environment were seriously ill emphasizing the need for burn care practitioners to possess complex set of skills to deliver care. Having such complex skills within a tertiary facility led to the perception among patients and families that survival was guaranteed irrespective of the condition: *"...the belief is that the hospital is a bigger institution and the problem will be solved by all means"* (PHY003)

Participants mentioned that though they may suspect the most probable outcomes for some severely injured patients, other patients who were presumed to be improving could die suddenly. For burn patients with poor prognosis, participants reiterated that the end of life phase remained unclear. For burn patients who died suddenly, there appeared to be no distinct end of life phase as acute care continued till sudden death. These experiences made the burn care environment highly unpredictable with a feeling of hanging in a balance: *"...everyone feels like this patient is okay, and then suddenly, they*

*die. It is even more difficult in such instances.” (RN009).* Participants highlighted that the burn care environment was situated within a wider context where death was sacred and not talked about until it has occurred: *“...in our culture, we don’t talk about death and so that becomes difficult.” (PT001)*

### ***Care processes and relationships***

Participants mentioned that in providing care, bonds were formed between them and the patients that got them knowing each other beyond wounds and uniforms. This led to the development of trust and confidence in the healthcare provider. The practitioners therefore wanted to do their best. These trust relationships, together with the belief of attaining cure at a tertiary facility, heightened patient expectation that they would survive the injury. Thus, when the patient died suddenly, participants felt they had failed: *“With the sudden death like that, I feel I have failed because I am supposed to be the gap between life and death.” (RN005)*

For patients with poor prognosis, participants highlighted experiencing difficulties when conveying this to the family. This was because relatives may have interpreted the wound healing process to mean that the patient was getting better. In instances where the family was financially drained, and the practitioners discussed worsening conditions, the family tend to relinquish the situation: *“...when they see the wounds are healing, they know the patient is getting better. They just believe that come what may, the patient must survive, and it can really take a bad note, some of them can lose it when you tell them that and stop coming to the hospital” (RN004)*

If the patient was deteriorating, active management is varied among the practitioners: whilst nurses escalated their care, physiotherapists de-escalated their care by reducing the intensity and frequency of therapies. The motive for escalating and de-escalating care was to avoid guilt feeling:

*"..you're not the reason why the patient died. So, for me I think if they are going down like that, then we do not do much, we kind of withdraw our services."*  
(PT002)

*"At the same time, you try and do your best for the patient, bathe them and check on them so that even when they go you know you did all you had to do"* (RN008)

The period around death was marked by many emotions. Breaking the news of the death to family members, was a difficult task which fell mostly on the nurses. This was more difficult if the patient had died suddenly: *"we do our best. If you are on duty and the patient dies and you must break the news, that is another difficult thing, especially if the patient was okay"* (RN003). Sudden death experiences also led to questioning one's skills with feelings of devastation and grieving on their own without expressing it openly: *"...You just go and grieve on your own somewhere and it continues like that."* (PHY004)

### **Perceived patient needs at the end of life**

Participants described their perceptions of the patient needs in the period preceding death as discussed below:

#### ***Physical needs***

Participants mentioned pain as a physical need. Practitioners noted that patients' feelings of loneliness could exacerbate their pain: *"...some of them don't have people visiting them and can make them feel lonely and worsen their pain"* (PT004). Patients with deteriorating condition were noted to be unable to tolerate oral feeding leading to emaciation: *"Physically they do not eat so they emaciate, they lose weight"* (PHY003). As their condition deteriorated further, participants indicated that the patients became increasingly dependent on others: *"...they need to rely so much on people to get things done"* (PT002). Participants mentioned that the patients sometimes demonstrated challenges interacting with others: *"...the patient can become confused, unable to talk well and cannot remember even the family"* (RN001). Some became unconscious with

breathing difficulties: *"You can really see the patient is struggling to breathe and their output just goes low no matter the amount of fluids you give"* (PHY0002)

### ***Socio-economic needs***

Participants noted that strict visiting policies limited the time that families spent with the patients: *"...we don't have space for them to build memories. What we see is visiting hours are over, so they have to leave"* (PT003). Some patients felt abandoned by their families due to financial constraints and the emotional impact of the situation. For some patients, it was at this point that they wished to make amends: *"...some of their relatives get tired with it all and stop coming to see them, they feel rejected and lonely."* (RN008)

### ***Psychological Needs***

Participants mentioned worry, guilt and regret as psychological concerns. Patient worry was expressed by concern about their families. Patients felt guilty for having to rely on others for their needs and expressed regrets when they reflected on the injury occurrence: *"...a lot of them have regrets with this sense of not being enough, because for some patients before they got to that stage, they were very able, doing things on their own. It's difficult for them to accept the fact that they need to rely on others."* (PT002)

### ***Religious Needs***

Participants mentioned that burn patients sometimes expressed fear of dying and the need to relate to God: *"...some of them are in fear because no one knows what is on the other side... the patients made a statement that gave me a clue that spiritually they wanted to be right with God"* (RN003)

### **Considerations for Palliative Care in Burns**

Recommendations regarding palliative care in the burn unit that emerged during the interviews and consultative meeting are described below:

### ***Integrated Care***

Participants highlighted that palliative care should commence alongside active treatment for severely burned patients: *"...the extra that we have to add is to start from admission to follow protocols in caring for the patient with poor prognosis"* (PHY). Participants noted that attaining this form of care required collaboration: *"...there is a palliative care team in the hospital, we can link up with them."* (RN)

### ***Availability of support***

Participants highlighted the need for counseling, education, and financial support for patients and relatives. Participants mentioned that relatives should be 'guided' through the process as goals of care change rather than just 'telling them': *"...telling them is not enough we have to let them know what it means, what is actually going on and where we are heading to. They must be guided."* (RN) as well as providing liberal visiting hours that allowed the family to spend adequate time with patients: *"...in that case we can be more flexible with them during visiting hours"* (PHY)

### ***Training needs of practitioners***

Participants wanted further training to enhance their clinical skills: *"I think we require a lot of training in end of life care."* (RN). Additionally, protocols were needed to guide staff at the end of life: *"...there should be a formal protocol with respect to end of life care in our unit."* (PHY)

### **Discussion**

This study describes the complex nature of providing end of life care. The experiences suggest that though there may triggers for the initiation of end of life care, the timing is loosely defined albeit with some deaths occurring suddenly. The findings indicate a process of complex decision making with prognostic uncertainty and a feeling of hanging in a balance. Though several needs may emerge, the findings suggest the possibility of reactive care. The findings may support a robust system of care which can facilitate commencing palliative care alongside active treatment where appropriate. Guidelines in

this regard will focus on communication, symptom management, and post-bereavement support for relatives and staff.

Burns can result in tremendous physiological stress. Though Sheppard and colleagues have argued for the need to consider biochemical markers in prognostication<sup>26</sup>, there is a global agreement that total burn surface area (TBSA) and age are central.<sup>2, 27</sup> Findings from the current study suggest that although participants are familiar with these variables, prognostic uncertainty is a reality. Moreover, the Ghanaian socio-cultural system does not encourage discussing death as it is considered a taboo to do so<sup>28</sup>, thus, limiting readiness to discuss poor prognosis. Clinicians may therefore use euphemisms to cloak the information they give.<sup>29</sup> Following the death of the patient, clinicians experienced feelings of failure and difficulty in breaking the death news. To resolve these issues, Krawczyk and Gallagher suggest the creation of prognostic awareness in an ongoing manner.<sup>29</sup> Creating this form of prognostic awareness, however, may require culturally sensitive communication.

In this study, financial status emerged as a concern adversely affecting patient outcomes. Burn care is expensive with an average cost of US\$88,218 per burn patient in high income settings<sup>30</sup> and US\$15,250 in a developing setting.<sup>31</sup> Similar to other LMICs, burn care costs in Ghana are not entirely covered by existing health insurance such that burn patients/ families need to bear costs out of pocket. Though the exact cost associated with burns care has not been empirically evaluated in Ghana, a previous study has noted that hospitalization with major burns may deplete the family's financial resources.<sup>32</sup> Some studies have observed that palliative care may reduce poverty through home-based care,<sup>33-35</sup> however the nature of severe burns cannot permit affected persons to be catered for in the home. More innovative healthcare financing measures such as welfare schemes and burn-specific donation maybe considered.

This study offers direction on guidelines that may be applicable to the burns setting. The guideline should focus on communication, symptom management and post-bereavement

support for the family. Though these components align with the delivery of palliative care in critical care units, the findings revealed that support for burn care staff is important as they experience grief. The components identified in the current study are also similar to the Burn Modified Liverpool Care Pathway (BM-LCP).<sup>36</sup> However, whilst the current study point to commencing this pathway alongside active treatment following admission of severely burned patients, The BM-LCP pathway only followed a futility decision and therefore did not support some patients who died suddenly. Our findings from this study suggest initiating palliative care alongside active burns therapy particularly for severely injured patients and escalating when needed. A similar strategy has been reported by Mosenthal and colleagues for patients admitted to the trauma ICU.<sup>37</sup> Besides, this strategy is supported by the WHO position that palliative care is applicable early in the management process and can be utilized alongside active treatment to promote dignity.

Conceptualizing and defining good death may include components such as emotional well-being, dignity, and quality of life.<sup>38</sup> Though the study suggest that burn patients at the end of life may wish to make amends, the sudden nature of burn death may not permit its timely resolution which may heighten the feelings of regret. This strengthens the need for early integration of palliative care to improve end of life care outcomes.<sup>39</sup> As highlighted in recent studies, patient outcomes at the end of life remain critical gaps to be resolved.<sup>40, 41</sup> Incorporating these outcomes in a collaborative practice that enhances the timely utilisation of palliative care, facilitates communication/ shared decision making and offers post-bereavement support to families and clinicians could represent avenues for future research.<sup>40-43</sup> Further training as noted in the current study and resonated in previous studies remains paramount in achieving an integrated model of care.<sup>44, 45</sup>

### **Strength and limitations**

The strength of our study lies in use of a multi-method approach to understand participants' experiences. Despite this, there are some limitations. Firstly, the study included only clinicians from a developing country which may limit the transferability of



the findings. Secondly, only participants with a minimum of 6 months working experience were recruited. Given the nature of death, it is likely that new practitioners may experience it differently.

### **Implications for practice**

Practitioners' experiences suggest a poorly defined end of life period with some deaths occurring suddenly. In a setting like ours, prognostication goes beyond clinical indices to include financial status. The findings suggest a need to commence palliative care alongside active treatment. Guidelines should focus on communication, symptom management and post-bereavement support for relatives and staff.

### **Declarations**

### **Authorship**

JB, KB and RH conceptualised the study; GA, PKB & JB undertook data collection; All authors participated in the data analysis; JB, KB, & RH drafted the article; all authors critically revised the manuscript and approved the final version for publication.

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### **Declaration of conflicting interest**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article

### **Ethics and consent**

Ethical approval was obtained from the Kings College, London, and Komfo Anokye Teaching Hospital.

### **Data management and sharing**

Transcriptions may be made available on request by contacting the corresponding author on [jbayuo88@gmail.com](mailto:jbayuo88@gmail.com).

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